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Gimp Anthropology:
Non-Apparent Disabilities and Navigating the Social

by

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ABSTRACT

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Individuals with non-apparent, physical disabilities face unique social challenges from those that are encountered by the more visibly disabled. The absence of visible cues indicating physical impairment causes ambiguity in social situations, leaving the sufferer vulnerable to moral judgments and social sanctions when they are unable to embody and perform to cultural norms. This dynamic generates a closeted status that the individual must learn to navigate. Using Eve Sedgwick's "The Epistemology of the Closet," this paper deploys auto-ethnography, traditional ethnographic techniques, and literature reviews to illuminate a third space of functioning between the outwardly 'healthy' and the visibly disabled.

ACKNOWLEDGEMENTS

My graduate journey has been a challenging one to say the least, and certainly I would not have made it this far without the support and advice of my family, friends, and my thesis committee – most especially my mentor, the long-suffering Dr. F. (Professor James D. Faubion).

I also have to acknowledge the brave anthropological giants on whose shoulders my argument stands: Emily Martin, Susan DiGiacomo, Susan Wendell, and Susan Greenhalgh. They made their personal health struggles a centerpiece in their ethnographies, a project that I can now confirm is a supremely uncomfortable one. But it is desperately needed.

Finally—

If you've ever dreaded the phrase, "but you don't look sick"

If you can identify with the popular, morbid joke: "The good news is that it doesn't kill you, and the bad news is that it doesn't kill you" and

If you've ever heard me complain about these and offered me a kind, supportive, and judgment-free word

— then this effort is definitely dedicated to you.

R. Janice Orlando
Houston, Tx

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PREFACE
On Terminology

Before beginning my analysis, it would perhaps be prudent to address a few comments toward some of the terminology that I will frequently be employing; these include some main terms in my title, "Gimp Anthropology: Non-Apparent Disabilities and Navigating the Social." I use the phrase 'non-apparent disabilities' to denote a category in opposition to visible disabilities, which are sometimes referred to as 'handicaps,' in popular parlance. 'Invisibly disabled' or 'nonvisible disabled' are phrases that have been commonly used in academic studies and articles, but are nevertheless problematic terms because many people with non-apparent disabilities, myself included, have questioned the extent to which our personal health struggles are completely undetectable, if only one were paying attention.

Similarly, the term 'hidden disabilities' gives off the impression that some sort of sleight of hand is taking place – which incorporates an additional layer of judgment in addition to the impact of social failure arising from one's physical impairment not registering on one's outward appearance. And in fact, 'non-apparent' should really perhaps be *not immediately* apparent, as many chronically ill individuals tire quickly in social situations or frequently betray their fatigue or pain in their comportment. Finally, where possible I choose to say that a person *has* a non-apparent disability rather than using the noun-phrase "the non-apparent disabled," not only because of the violence it does to the English language, but more importantly that it tends to create a false picture of the totally disabled person – as if every faculty was profoundly disabled in every way – an inert human being.

The word ‘gimp’ is a piece of derogatory slang, originating in the United States. It has several meanings. The Oxford Dictionary of Modern Slang [1] offers the following definitions:

gimp[1] – *noun* Courage, guts.

gimp[2] – *noun* 1. A lame person or leg

verb intr. 2. To limp, hobble

gimp[3]— *noun* A stupid or contemptible person

And, for slightly more ethnographic purposes, the top-voted result for ‘gimp’ on the popular reference website Urban Dictionary [2]:

(1) A derrogatory [*sic*] term for someone that is disabled or has a medicial [*sic*] problem that results in physical impairment.

(2) An insult implying that someone is incompetent, stupid, etc. Can also be used to imply that the person is uncool or can’t/won’t do what everyone else is doing.

My usage of ‘gimp’ does several things. Firstly I want to call attention to the fact that I, an anthropologist, personally suffer with a non-apparent disability; it is variously

[1] John Ayto and John Simpson, “gimp[1] noun,” *Oxford Dictionary of Modern Slang, Oxford Reference Online* (Oxford University Press), Rice University, accessed April 7, 2012, http://www.oxfordreference.com.ezproxy.rice.edu/views/ENTRY.html?subview=Main&entry=t291.e1757
John Ayto and John Simpson, “gimp[2] noun,” *Oxford Dictionary of Modern Slang, Oxford Reference Online* (Oxford University Press), Rice University, accessed April 7, 2012, http://www.oxfordreference.com.ezproxy.rice.edu/views/ENTRY.html?subview=Main&entry=t291.e1758
John Ayto and John Simpson, “gimp[3] noun,” *Oxford Dictionary of Modern Slang, Oxford Reference Online* (Oxford University Press), Rice University, accessed April 7, 2012, http://www.oxfordreference.com.ezproxy.rice.edu/views/ENTRY.html?subview=Main&entry=t291.e1759

[2] Pymp, November 1, 2003, “gimp,” *Urban Dictionary*, accessed April 7, 2012, <http://www.urbandictionary.com/define.php?term=Gimp>

called Chronic Fatigue Syndrome (CFS), Chronic Fatigue and Immunodeficiency Syndrome (CFIDS), or Myalgic Encephalomyelitis (ME). Later in my analysis I will discuss how diagnostic labels change depending upon gender, geopolitical location, and physician – but for now it is vital that I immediately call attention to my own positionality [3] as 'native' ethnographer, or perhaps more accurately - that I am deploying autoethnography.

Secondly, I am writing about the struggles of individuals who must suffer, often silently, not only with physical, emotional, and mental distress, but also with the constant moral judgments that are imposed upon them as they simply try to navigate their everyday social lives. Because of this, in using the term 'gimp' I wish to make a gesture toward the history of subordinated groups reclaiming once-denigrating terms. 'Queer' comes specifically to mind; the reasons for this will become clearer later, but it is related to my main point: that there is a third space of functioning between the healthy/disabled binary, and it is this space that I am trying to illuminate.

[3] For a cogent discussion of the concept of positionality as seen through the lenses of Heidegger and Gadamer, see Allaine Cerwonka and Liisa H. Malki, *Improvising Theory: Process and Temporality in Ethnographic Fieldwork* (University of Chicago Press, 2007), 25-33.

INTRODUCTION

> It's the person as resource base and maximization is the goal – through education, through investment, through all these different modalities to continuously maximize potential – that I think is what's emerging as a model of the person in the world. There are enormously disturbing things about that, not the least of which is the extent to which it cuts off whole sectors of the population from even participating because it's so costly. It's very easy to think about this in terms of Darwinian fitness. Wherever the cutoff point is, that's where it has to be, you know. [4]
>
> -Emily Martin

When I was around 15 years of age, I had what I thought at the time was a horrible case of Mono. For months I spent most of my days in bed; I could stagger sometimes to the living room couch, spending time with my family but yearning to go back to bed. Muscles became weak, mind foggy, mood dismal. Blood tests showed no evidence of any mononucleosis having ever been in my system. Several confused general practitioners and a pediatric rheumatologist later, I had a diagnosis of Fibromyalgia Syndrome (FMS). Sixteen years old and I was in physical therapy over what I had initially thought was a bad cold. At first, I'd had the unfortunately common, but nonetheless still unpleasant, experience of having a doctor dismiss my symptoms as depression.

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[4] Suzanna R. Kirchner, "From Flexible Bodies to Fluid Minds: An Interview with Emily Martin," *Ethos* 27.3 (1999): 269.

Finally as time progressed and I approached adulthood, I began to be taken seriously. It helped that I'd been taking a college class at the local community college. That seemed to catch a doctor's interest. Clearly I was a go-getter, so *something* must be holding me back. Finally, nearly 10 years after my initial diagnosis of FMS, I began to be treated for Chronic Fatigue Syndrome (CFS), and started to experience some real relief from my symptoms. My doctor is an expert on the immune system who treats predominantly AIDS patients and people with chronic illnesses like CFS or FMS. The two categories of illness have significant overlap in that immune system dysfunction is a hallmark of both, a discovery that came out of AIDS research and which has benefited people with CFS. With new etiological hypotheses come new blood tests, and even thought I didn't entirely understand what was being measured, I nevertheless experienced a validation of my symptoms, through quantifiable biomedical tests, for the first time.

It was a long journey to reach this place. Not only have scientists discovered more information about chronic illnesses, which is also undoubtedly the case, but also doctors have slowly, ever so slowly, awakened to the possibility that patients are not making themselves ill. Almost the first thing that you learn from having a non-apparent, disabling chronic illness is that doctors are varied and fallible. Previously, you might have assumed (as I did, I confess) that because all doctors must meet a certain objective threshold of skill, achievement and knowledge, that therefore when each are presented with the same set of symptoms and test results most doctors would logically reach the same sort of conclusions. This is an enormous fallacy that becomes almost instantly apparent. The lore of the stigmatized, as Goffman (1963) notes, is full of war stories; the chronically ill often swap their tales of doctor's appointments gone horribly, horribly wrong. One of my

interlocutors described 10 years of being written off as depressed, until finally, in desperation, they enlisted a roommate of 3 months to come 'testify' to the doctor that they didn't consider their friend depressed. It finally worked; the person was diagnosed and treated for CFS and a sleep disorder. After ten years of angst and frustration.

It's an especially cruel mechanism that drives a person, already plagued with miserable new symptoms, so far down that they start to wonder, 'Am I really causing this? I don't want continuous pain, awful sleep, muscle weakness… I don't suffer because I need attention. What good is a pat on the shoulder and a 'feel better' to the ability to run outside or play on a skateboard?' (This is what I wondered when I was 15, anyway.) Everyone with a chronic illness has to go through this stage: when the doctors, the culture, your peers – when everyone says "you can do it, you can (make yourself) feel better." But you really, just, can't. Much more than a mere capacity to empathize with another's bodily suffering – this experience cements a knowledge that, once 'earned,' gives you an acute awareness of what it might be like to be that other person struggling with their chronic illness. Levels of disability differ, perhaps someone else isn't quite disabled (and hopefully won't be), the symptoms and their intensities are not the same – but this particular experience is a common one. It is on the level of the social, not the biological, this suffering.

Non-Apparent Disabilities & Navigating the Social

Individuals with non-apparent, physical disabilities face unique social challenges from those that are encountered by the more visibly disabled. The absence of visible cues indicating physical impairment causes ambiguity in social situations, leaving the sufferer vulnerable to moral judgments and social sanctions when they are unable to embody and perform to cultural norms. This dynamic generates a closeted status that the individual must learn to navigate. Using Eve Sedgwick's (1990) "The Epistemology of the Closet," this paper deploys autoethnography, traditional ethnographic techniques, and literature reviews to illuminate a third space of functioning between the outwardly 'healthy' and the visibly disabled.

Structurally, each chapter in this paper seeks to explore one facet of this third space: 1) living not only with near-constant discomfort but also with personal and identity delegitimation due to the "epistemological purgatory" [5] of their health status; 2) claiming the authority of one's own "illness narrative," [6] even as experts actively engage in undermining it; and finally 3) the closeted mechanisms of managing stigma and identity in social settings and interactions. The first chapter, "The Epistemology of Non-Apparent Disabilities," seeks to ground the category by differentiating a group of "contested illnesses" from among the larger category of potentially disabling, non-

[5] Kristin Barker, "Self-Help Literature and the Making of an Illness Identity: The Case of Fibromyalgia Syndrome (FMS)," *Social Problems* 49.3 (2002): 279-300.
[6] Arthur Kleinman, *The Illness Narratives: suffering, healing, and the human condition* (Basic Books, 1998).

apparent illnesses, thus focusing the scope of the argument. Contested illnesses are "diseases and conditions that engender major scientific disputes and extensive public debates over environmental causes" (Brown, et al. 2001:236). This unstable biomedical ground denies sufferers not only treatments which may reduce the frequency or intensity of symptoms, but also withholds from them the means to make their illness experiences intelligible to others (Shriver & Waskul 2006; Dawes 1991; Kleinman 1992). In addition, many contested chronic illnesses, such as CFS or FMS, are overwhelmingly gendered as female (Åsbring & Narvanen 2002; Pheby 1999; Prins 2006); this discourages men from seeking treatment and may also bias doctors and thereby contribute to under-diagnosis in men. This generates an incredible amount of stress in addition to learning how to function with new health challenges, to say nothing of the impact on personal identity and hopes or goals for the future (Bury 1982; Charmaz 1995; Clarke & James 2003).

Finally, when a person has reached the threshold of disability, the stigma that comes with embracing the label is supposed to be mitigated, at least in part, by the political and institutional mechanisms set in place for the disabled. However, the political goals of the disability community at large have been highly skewed toward a paradigm of the non-chronically ill, predictably impaired, "healthy disabled" (Wendell 2001, 1996). Accommodations for wheelchair use or technology to mitigate hearing and sight impairments are fairly straight forward measures which, due to the hard work of disability advocates, have become nearly a given in most institutional and work settings within the United States. Thus the majority of accommodations processes currently in place are designed with such impairments in mind, and individuals with non-apparent

disabilities are forced to work much harder to negotiate for accommodations which may be more relevant to their needs (Jung 2002).

Chapter 2 addresses the intimidating challenges which face individuals who are struggling to assert their voice as authentic and authoritative when sharing their personal illness narratives. Unequal power relations fostered by a discrepancy in credentials and expertise can work against individuals trying to stake claims to personal truths. One of these scenarios is a well-documented one: when patients are speaking (or trying to speak) to their physicians. Patriarchal cultural norms shape the doctor-patient encounter. Ironically, in the quest to unpack this dynamic, academic analysts have sometimes inadvertently re-challenged the authority of the speaking patient. These experts, while speaking eloquently on the plight of the subordinated, often end up deploying the authority of their own expertise to speak *on behalf of* the Other rather than affirming their right to speak for themselves. The critical biomedical discourse that speaks against the 'medicalization' or 'reification of illness' is a prime example; by denying an individual the agency and capability to understand, define, and describe his or her own suffering, this discourse constructs a particularly devastating challenge to personal illness narratives. [7]

Having attended to the epistemological grounds of non-apparent disabilities, the devastating effects that they have on an individual due to constantly changing bodily challenges, and the obstacles that often seek to undermine or confound their ability to claim them, it is time to put these lived experiences into a conceptual framework.

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[7] For a useful overview of feminist and other critical medical theories see Deborah Lupton, "Foucault and the medicalisation critique," in *Foucault: Health and Medicine,* Alan Petersen and Robin Bunton, eds., (London: Routledge, 1997): 94-112.

Because the stigma in this case is not immediately visible, it puts the stigmatized in the category of the "discreditable" (Goffman 1963:4). As such, the management of information becomes a central pivot point in social interactions. The dynamics of living with a non-apparent disability suggests a fruitful engagement with the concept of the queer "closet." After first tempering the framework with an evaluation of the usefulness and weaknesses of this analytic comparison, I will use the work of Goffman and Sedgwick, along with personal insights from key informants, to explore the pitfalls and double-binds that are seemingly inherent in the management of identities both queer and non-apparent disabled, alone and combined.

Models and Methodologies

Clearly this thesis is one project with a definite autoethnographic flavor, as I personally have a non-apparent disability. But far from being an indulgent project of self-absorption, an accusation leveled against many autoethnographies, [8] I very much hesitated to write on this subject. My undergraduate degree is in East Asian Studies and Languages and it was my intention to take my language skills and interests in Media Anthropology and go off to Japan and South Korea for the doing of fieldwork. [9] But as it

[8] See especially Geertz 1988; and Rosaldo 1993.
[9] As Marcus (1998) attests, this type of ethnographic endeavor is regarded within the discipline as a much more traditional 'First Project.'

turns out, the idea that I could, with my chronic illness always in tow, traipse off across the globe alone – without the support system of my family and friends – was rather over-ambitious.

Despite this rude awakening, I understood that my dual position as a scholar-in-training and a chronically ill, disabled person was rather unique; and while mostly exasperating (for my department too, I suspect), this position that I have found myself in presented a good opportunity, maybe even an obligation, to try and turn a setback into a means of contributing an analysis that could potentially help to illuminate the mysterious world of a people who must learn to navigate their lives by a third mode of functioning. Neither 'healthy' nor 'visibly disabled,' they live their lives with non-apparent disabilities.

Nor am I the first scholar to write an analysis deeply influenced by her own experiences. While finishing up her dissertation research, Susan DiGiacomo was diagnosed with Hodgkin's disease; reflecting on her challenges through ethnography was a way for her to cope. She emphasized that writing about her experiences of suffering was not a way to cast herself as, using Susan Sontag's term, "the anthropologist as hero" [10] nor was she exerting herself in a bid to be “at best self-absorbed and pretentious, and at worst nihilistic”(DiGiacomo 1992:111). Neither was Emily Martin, who researched women's reproductive health even as she herself was pregnant; and then later, as she wrote an ethnography on Bipolar disorder, something that she personally suffers with. In an interview, Martin once reflected on how taboo it was in the discipline to write about personal topics, and she struggled with how to approach it in an ethnographically

[10] Susan Sontag, “The Anthropologist as Hero,” in *Claude Levi-Strauss: The Anthropologist as Hero*, ed. E. N. Hayes and T. Hayes, (Cambridge: MIT Press, 1970 [1963]), 184-196.

rigorous way. Finally she came to the realization that, “there’s no trick here. There’s no trick at all. All I have to do is…pay close attention to what people say and find it amazing” (Kirschner 1999:252).

So in order to prevent my analysis from being merely a generalization based upon my own experiences, in addition to literature review I will employ the more traditional ethnographic techniques of anonymous survey results along with insights gained from semi-structured and informal interviews. These strategies were employed to solicit reflections on what it's like to live with chronic illnesses, and to glean insights about the obstacles that the non-obviousness of their challenges pose to smoothly navigating through their social lives. I wrote an online survey entitled "Living with Non-Apparent Disabilities" and received 29 responses. (I have included the text of the survey in an appendix.) The survey link was posted, via the social networking site Facebook, to two public pages run by activist/advocacy groups that center around awareness for people living with invisible disabilities.[11] Additionally, from among my acquaintances I selected two key informants for interviews; one of these people I know in person, and the other is someone I know primarily from exchanges through online social networking. [12]

Methodologically, I drew a line between my family, close friends and my interlocutors. Though I have quite a number of family, friends, and colleagues each living their lives with disabling chronic illnesses, I chose to view them as part of my intimate social network –and thus part of my autoethnographic sources of knowledge. My support networks are what keep me going, and what shape and give form to my ideas about my

[11] Their term.
[12] As Nikolas Rose and Carlos Nuvos have pointed out, the internet is a facilitator of "digital bio-citizenship" (2005:442). Luckily for me, they were right.

own life with chronic illnesses and of others as well. And who is to say that my own experience is anything like another's? As an American middle-class, single, young (late 20s) white woman, I know better than to try and generalize from my own position. Instead, following Cerwonka and Malkki (2007), I have chosen to deploy my specific "vantage point," meaning that I purposefully use the fact that I occupy a particular "sociohistorical location" and have my own set of "priorities, questions, [and] hypotheses that one inevitably brings to bear in trying to understand an object or phenomenon" (26).

But this is not to assert that all autoethnographies or autoethnographically-informed projects are necessarily analytically equal. I found Anderson's (2006) essay, "Analytic Autoethnography," to be a useful overview of different autoethnographic strategies and critiques; he proposes a general framework for how to construct an analytically rich autoethnographic analysis. In contradistinction to the 'evocative autoethnography' model, which seeks primarily to evoke an emotional response in the reader,[13] Anderson champions his formulation of the "analytic autoethnography." It requires three elements: that the researcher be "a full member in the research group or setting," that this fact be made visible, and lastly that the researcher is "committed to developing theoretical understandings of broader social phenomena" (373). The chosen exemplar of this species of autoethnography is the excellent work of Robert Murphy in his book *The Body Silent* (1987). Murphy wrote about his body's slow transformation into a state of quadriplegia due to a growing tumor. Incredibly personal while also analytically rich, Murphy's work "forcefully demonstrates that deeply personal and self-observant

[13] See for instance the works of Carolyn Ellis and Arthur Bochner.

ethnography can rise above idiographic particularity to address broader theoretical issues" (Anderson 2006:379).

In any case, as many scholars have pointed out, there is no such thing as an ethnography without bias;[14] making evaluative judgments on research materials, the statements of interlocutors, and the narrative or theoretical strategies used to frame them are all situated practices: "To say that understanding is always a situated practice is not simply to acknowledge that we always bring personal 'bias' (conceptual and personal fore-understandings and prejudgments) to our research. It is to say that we always understand through a set of priorities and questions that we bring to the phenomenon/object we are researching" (Cerwonka & Malkki 2007:28). While not taking myself as the center of analysis, I want to especially draw attention to the fact that my own experiences both social and embodied have influenced the questions that I ask, and how I evaluate and derive meaning from the answers.

[14] Among the most impactful of these has been *Writing Culture: The Poetics and Politics of Ethnography*, eds. James Clifford and George Marcus, Berkeley: University of California Press, 1986.

CHAPTER 1
The Epistemology of Non-Apparent Disabilities

Non-apparent disabilities come in many forms and varieties, but their key underlying characteristics, for analytical purposes, is that they 1) induce bodily suffering that interferes with the functioning of everyday life [15] and 2) do not immediately register on an individual's outward appearance. However, this definition is still over-broad; it still covers various cognitive, behavioral, or mental conditions (such as ADD/ADHD, Bipolar, etc.), auto-immune conditions (Lymes disease, Lupus, Celiac, Crohns), rheumatoid arthritis, diabetes, multiple sclerosis (MS), and what I will call "contested illnesses," also referred to as diagnoses of exclusion. These include Chronic Fatigue Syndrome (CFS)/Myalgic Encephalomyelitus (ME), Fibromyalgia (FM or FMS), and Gulf War Syndrome or Gulf War Related Illnesses (GWRIs) (Shriver & Waskul, 2006; Brown, et al. 2001). Because I aim to illuminate the particular *social* dimensions of living with non-apparent disabilities, my analysis will still to some extent apply to all of the above categories, but it is these last cluster of so-called contested illnesses that I am particularly interested in. [16]

There are several reasons for this. First, their fraught epidemiological status means that there is constant confusion and uncertainty over possible causes, treatments, and even which 'proper' diagnostic nomenclature should be used. Second, when this

[15] Here I am borrowing from the Americans with Disabilities Act (1990)
[16] For a necessarily verbose but elegant discussion that, while also attending to the unique challenges faced by people with "invisible disabilities," still manages to incorporate the different valences of disability, see N. Ann Davis, "Invisible Disability," *Ethics* 116.1 (2005): 153-213.

shaky biomedical grounding is coupled with the nature of these illnesses as *chronic illnesses*, which can be cyclical and fluctuate over time, we can see why they are particularly suited to an analysis of cultural norms and social friction; bodies with such illnesses fail to be flexible and productive in a socially valued way (Martin 1994). These illnesses are constitutively different from what Western society more commonly (mis)understands as the nature of disability – that they are both predictable and consistently visible. Third, despite the not insignificant existence of male sufferers, these illnesses are overwhelming gendered as female in both research literature and popular belief. Finally, and not unimportantly, these illnesses are the ones that I am more intimately familiar with, as my own bodily suffering has been both popularly and diagnostically classified as belonging to this category.

CFS/CFIDS/ME; FMS; GWRIs

The act of naming contested illnesses is a politically charged one with far-reaching implications for health policy, physicians, and most importantly sufferers. Chronic Fatigue Syndrome, as it is known in the United States, got its name from the predominant symptom of a mysterious mononucleosis-like illness that struck the residents of Lake Tahoe, Nevada in 1984 (Holmes, et al., 1987). However, Evengård et al. (2011) connected the possible origins of CFS to a much older malady termed "neurasthenia" by a 19th century American neurologist (Beard, 1869). Because doctors

were scrambling to find evidence of a pathogen or other cause, and because it initially was thought to occur predominantly among Caucasian middle or upper-class women, for a time it was referred to laughingly as the 'yuppie flu' in the popular media. This stigmatizing label long haunted anyone who sought, or considering seeking, treatment for similar symptoms. Despite successful lobbying efforts, it wasn't only the medical community and the popular media that failed to take the situation seriously. In 1999 the United States Centers for Disease Control (CDC) acknowledged that it had re-directed millions of dollars, dedicated by Congress for CFS research, to other projects. [17] Both CFS and FMS are still considered somewhat of a 'women's' disease, especially within the United States, but as I will argue later on, this may be due to sampling biases in research, varying and gendered health-seeking behaviors, the gendered assumptions of diagnosing physicians, and the stigma of possibly being diagnosed with a disease coded as feminine.

Though diagnostically CFS denotes a myriad of other symptoms, the name causes immediate confusion with Chronic Fatigue, also a diagnostic phrase. Chronic fatigue is a symptom that can be caused by any number of things, including many other illnesses, contested or otherwise, or simply from "modern living" (Beard, 1869). The word 'syndrome' is itself embedded in a web of meanings. The choice of 'disease,' 'disorder,' and 'syndrome' has implications for both biomedical legitimacy and by extension where the malady is thought to fall on the West's recalcitrant mind/body paradigm. 'Syndrome' is a collection of symptoms with no known biological cause, and is frequently used in psychiatry. Former illnesses that later achieved biomedical legitimacy include AIDS

[17] David Tuller, "Chronic Fatigue No Longer Seen As 'Yuppie Flu,'" *The New York Times: Frontline Report*, July 17, 2007, accessed April 11, 2012, http://www.nytimes.com/2007/07/17/science/17fatigue.html.

(acquired immune deficiency syndrome) and SARS (severe acute respiratory syndrome). The phrase, 'Chronic Fatigue Syndrome' has been criticized by patients for its origins in psychiatric literature, and a 2004 survey confirmed overwhelmingly that CFS patients want the name to be changed (Jason et al., 2004).

Importantly for those suffering with CFS, the confusion between it and the symptom chronic fatigue is highly problematic in social situations, because outsiders (by which I mean those not fluent in the parlance of chronic illness) usually assume that the person is referring to sensations that they can easily identify with, such as feelings of tiredness or fatigue resulting from overwork, or sleepiness related to insufficient sleep. Though this 'outsider' may wish to help a suffering friend feel less isolated amongst their suffering, the usual result is misunderstanding on their part and frustration for the friend. According to several studies by the CDC, the level of fatigue due to CFS has been compared to that experienced by cancer patients after chemotherapy treatments, end stage renal failure, multiple sclerosis, and end stage AIDS patients.[18] Sleep does nothing to relieve it; an all-encompassing fatigue of both mind and body, it can be utterly debilitating.

In any case, however the fatigue is described or quantified, it is not the only CFS symptom that individuals are forced to function with; they may have one or more of the following: muscle pain and weakness, abnormally low or high body temperatures, sensitivity to light and sound, headaches, swollen lymph nodes, post-exertional malaise (defined as an inappropriate amount of pain and fatigue as a result of 'normal' exertion),

[18] For an online index of the CDC's publications on CFS, see http://www.cdc.gov/cfs/publications/index.html.

and various cognitive and memory impairments are common (Fukuda, et. al., 1994). Added to these symptoms are a whole host of additional discomforts that may arise from the side-effects of medications and other treatments meant to lessen the original symptoms. For all of the above reasons, advocates within the United States have embraced the name 'Chronic Fatigue and Immunodeficiency Syndrome' (CFIDS) to reflect findings which posit immune system complications and dysfunctions within the etiology of the illness. Nevertheless, the name Chronic Fatigue Syndrome still persists in both lay and research literatures.

Meanwhile, in the United Kingdom and among the Commonwealth nations, the illness has been known as ME, or 'Myalgic Encephalomyelitus.' The documented onset of ME in the United Kingdom dates from a 1955 outbreak of a mysterious illness at the Royal Free Hospital; though it was later attributed to a case of "mass hysteria," ME symptoms nevertheless continued to pop-up (Ramsay & O'Sullivan, 1956; Richardson, AT., 1956; McEvedy & Beard, 1970; Evengård, B., et al. 1999). As of 2011, the National Health Service estimated that around 250,000 people in the UK were suffering with ME.[19] 'Myalgia' refers to muscle pain, and 'encephalomyelitus' [20] to inflammation of the brain and spinal cord, which is what researchers initially thought the illness was related to. In the past decade, however, officials in the UK have recommended dropping ME in favor of CFS because there is little evidence that inflammation of the spine or spinal cord is involved (Evengård, B., et al. 1999).

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[19] "Chronic fatigue syndrome," *NHS Choices*, July 13, 2011, accessed April 11, 2012, http://www.nhs.uk/conditions/Chronic-fatigue-syndrome/Pages/Introduction.aspx.
[20] Instead of 'encephalomyelitus' the 'E' in ME sometimes refers instead to 'encephalopathy.'

Fibromyalgia, or Fibromyalgia Syndrome, as it is also known, shares many overlapping symptoms with CFS. It also is a diagnosis of exclusion, meaning that tests are first run to rule out any other diseases which could potentially cause a patient's symptoms. 'Fibromyalgia' literally means 'fibrous muscle pain,' and refers to pain in the muscles and connective tissue. One theory about FMS is that the brain is incorrectly processing pain signals, drastically lowering a person's tolerance for pain (Ngian et al. 2011). The co-morbidity of CFS and FMS is quite high; this has definitely been my own experience, and was also frequently mentioned in my survey results. From my personal perspective, I have often wondered if the two are essentially the same, except that fatigue is the prerogative of CFS, while pain that of FMS.[21] Symptoms include muscle pain, muscle tenderness, cognitive issues such a short-term memory loss or trouble concentrating (known as 'fibrofog'), un-refreshing sleep, fatigue, pelvic pain, and depression (Crofford 2012).

In 1999, the American College of Rheumatology released diagnostic guidelines which included the use of the 'tender point' test (Wolfe et al. 1999). A physician uses light finger pressure to touch certain spots on the patient's body, especially near their joints. In a normal person without FMS, this would seem ridiculous and cause no discomfort. But for someone with tender points, a feather-light touch can cause immediate and intense, searing pain. [22] Recently, the American College of Rheumatology has released new updated guidelines that do not require tender points, but instead focus on the report of the patient (Crofford 2012). This reflects the fact that not every person

[21] This is admittedly a gross simplification, but is nevertheless how I have attempted to differentiate the two in the past.

[22] Such a test was how I was initially diagnosed with FMS; it was extraordinarily painful, but also unsettling because I didn't expect it to be.

with FMS has tender points, something that used to be recognized as a hallmark. As with CFS, FMS is said to occur predominantly in women (Crofford 2012; Greenhalgh 2001). Perhaps unsurprisingly, the validity of Fibromyalgia as a distinct entity has been vigorously questioned (Wolfe 2009; Goldenberg 1995).

Though both CFS and FMS are gendered as female, and are diagnosed most predominantly in women, this final category of contested illnesses cannot say the same. The history of Gulf War Syndrome, or Gulf War Related Illnesses (GWRIs) is a particularly fascinating story. During deployment, soldiers complained of health problems, and these continued after they returned home from the 1991 Gulf War. Large numbers of them fell ill with mysterious symptoms like "sleep problems, mood swings, short-term memory loss, chronic fatigue, rashes, aching joints, headaches, abdominal pain, multiple chemical sensitivities, blurred vision, gastrointestinal problems, and sexual dysfunction," none of which bloodtests and medical examinations could account for (Shriver & Waskul 2006:466; Brown et al. 2000; Brown et al. 2003; Zavestoski et al.2002; Zavestoski et al. 2004).

In addition to the sufferers being overwhelmingly male, GWRIs are classified as *environmental illnesses*. Unlike CFS/FMS, GWRIs are not conceptualized as something that might lurk in the body, waiting to be triggered by some form of trauma or pathogen. Instead, they are attributed to outside causes, specifically environmental exposure. Prior to their deployment to Iraq, veterans were given large preemptive courses of vaccines;[23] and while deployed, they claim that they were exposed to both chemical and biological weaponry. Although the United States government initially denied that exposure occurred, they later admitted that "some soldiers were exposed to chemical agents near

[23] This fact is also mentioned frequently by advocates as a possible trigger for the illness

the Khamisiyah weapons depot after coalition forces destroyed it" but denied that such exposure necessarily correlates with illness (Shriver & Waskul 2006:466). If word of ill soldiers had gotten out, the U.S. Government would have a potentially tarnished image of such a hugely successful enemy defeat via technologically advanced surgical strikes (Brown et al. 2003:236).

While the gender of most GWRI would-be patients is male, their experiences are strikingly identical to those of CFS and FMS patients. Veterans describe being sent to psychiatrist after psychiatrist, since PTSD (post-traumatic stress disorder) was a prime way to excuse all manner of symptoms. And if their physical symptoms weren't immediately written off as PTSD (a rash, for example) they were explained away by the flimsiest of causes; in a desperate bid to find relief, veterans incurred thousands of dollars in debt seeking the opinions of private, non-VA doctors (Shriver & Waskul 2006).

Regardless of the name that describes a chronic, contested illness, whether it's chosen for descriptive purposes (Fibromyalgia), in a bid to sound more biomedically legitimate (Chronic Fatigue Immunodeficiency Syndrome), or to associate it with outside causes (Gulf War Syndrome), the experiences of the suffering are essentially the same. A strong soldier, an active mom, an energetic kid – any of these people could be healthy one moment, and fall grievously ill the next. Identities have to be repaired, life goals re-evaluated, and inner turmoil contained as they hop from frustrating doctor visit to frustrating doctor visit. And once they do find a sympathetic MD., there is still no cure for any of these chronic illnesses. Even with treatment, sometimes people will reach a new threshold; having transitioned from healthy to ill, they must now contend with moving from ill to disabled.

The Politics of Disability

> There is no reason to believe that the invisibility of a disability itself necessarily lessens its impact or makes the disability less serious. Though not as easily stigmatized in obvious or familiar ways, persons with invisible disabilities are subject to forms of rejection, humiliation, and social disapproval that are importantly similar. [24]

For a chronically ill person, the decision to incorporate the identity label 'disabled' is one that comes at great personal expense. It is not one imposed from without, as it is done with a certain violence to people with disabilities that they cannot hide. Instead, it can be a strategy of last resort, necessitated by a lack of health insurance or by job loss. Or it can slowly dawn on one, as life activity after life activity are slowly subsumed by the imperative to attend to various disruptive bodily symptoms and changing sensations. However the decision is reached, it is not done lightly, and usually because it is the lesser of two evils. Yet the non outwardly-obvious character of this type of disability means that social and institutional mechanisms of support and accommodation are sometimes out of reach, if only because it takes an incredible amount of energy and focus to pursue them.

This is partly the case because, as Susan Wendell (2001) describes, "it is safer and more comfortable for disability activism to focus on people who are healthy disabled" (19). Healthy disabled are people with disabilities who are "permanently and predictably impaired" (21). Their status does not change due to an illness, but instead they are forced to reckon with an impairment, a lack. But this is a framework imposed by dominant

[24] Davis, "Invisible disabilities," 154.

disability politics, and does not accurately reflect the full reality of disabled experiences. In contrast, an "ill" person is sickly, gimpy. They are not likely to join in competitive sports any time soon, and their condition may in fact worsen over time. There are in fact people with visible disabilities who are also chronically ill. And it is a reality often hidden under the political rug that certain impairments can indeed also cause illness down the road (Wade 1994). But the image of the inspirational disabled person achieving extraordinary feats despite 'adversity' is also, as Wendell points out, more comfortable for the nondisabled; people who can adhere to this image "can make others forget they are disabled" and therefore "will be allowed to participate most fully in the activities of their society" (22). Thus we can see that disabilities are not created equal.

The definition of disability itself is a moving target. I personally prefer the amended Americans with Disabilities Act (2008 [1990]), but Wendell (1996, 2001) provides an extremely useful analysis that incorporates the socio-cultural aspects as well as the biological or biomedical aspects of disability. To do this, she combines the United Nations 1983 definition of disability augmented by the observations of philosopher Ron Amundson. To summarize, there are two interrelated notions of disability; one is the biologically grounded impairment of a person's body, but this in itself does not constitute disability. Importantly, it is the impairment against the context of specific cultural and geospatial expectations of performance that renders an impairment a disability.

Within this framing, not meeting societal expectations such as literacy can come to be coded as a disability (cf. McDermott & Varenne 1995). This argument can be taken too far, if attention is lost on the physical suffering and becomes too focused on unfair societal expectations and 'able-isms.' This risks morphing into the anti-biomedicalization

or illness reification paradigms that are unfortunately all-too prevalent in critical feminist and other discourses on disability. This subject will be more fully attended to in the next chapter, however for now it will perhaps be more productive to turn away from the abstract and return again to realm of the everyday for persons visibly and 'invisibly' disabled.

An article from 1973 in the *Journal of Health and Social Behavior* provides a valuable outline of the differing social experiences among those with visible impairments versus those with invisible impairments. [25] Sociologists interviewed more than two thousand people who were receiving disability benefits in one of three metro locations: New Orleans, Minneapolis-St. Paul, and Columbus, Ohio. The data accounted for income levels, age, and gender. Far beyond anything that I could undertake alone, this study employed a diverse clinical team of experts including "social workers, doctors, psychologists, occupational therapists, and vocational counselors" to conduct "structured interviews…narrative reports, and laboratory tests" (118). The sociologists begin the article by outlining their initial hypotheses, and then go on to describe the ways in which the data either supported or refuted them; thus I believe this article is uniquely structured so that it is not only valuable to my argument because of the rich quantitative data it provides, but also because it lends itself to analysis as a cultural document in and of itself. By contrasting the researchers' initial expected results with their revised findings, we can get a fascinating glimpse into some of America's 'common sense' assumptions (even as they are also academic, educated assumptions) which center around the social lives of the disabled.

[25] Margaret A. Zahn, "Incapacity, Impotence and Invisible Impairment: Their Effects Upon Interpersonal Relations," *Journal of Health and Social Behavior* 14.2 (1973): 115-123.

The article begins by explaining the rationale behind conducting such a study in the first place – that while scholars had demonstrated the deleterious effects that visible impairments have upon social interaction, there had not been much specificity about the *kinds* of social interactions in which this was said to be taking place, nor had there been an accounting of just how impactful the impairments were vis-à-vis different social contexts: familial, conjugal, casual, etc. Specifically, the sociologists chose to focus on "interpersonal relations…includ[ing] relations with spouse, general family relations, relations with friends, and casual secondary encounters" (116). The facets of 'impairment' accounted for in the study were, "severity of the impairment; the kind of functional limitations associated with the impairment; and visibility of the impairment." Among the seven hypotheses put forward at the beginning of the study, the following are most pertinent to my analysis:

> *Hypothesis 1) As severity of physical limitation increases, the amount of disruption in interpersonal relations of the impaired increases.*
>
> *Hypothesis 4) The greater the loss in employment skills the greater will be the disability in all types of interpersonal relations.*
>
> *Hypothesis 6) Visibility will be more disruptive of secondary interpersonal relations than of primary relations.*
>
> *Hypothesis 7) Visible disorders will be more disruptive of interpersonal relations among young people than older people and among those in lower socioeconomic class.*

No initial justifications are provided for Hypothesis 1, but Hypothesis 4 was predicted to hold "more true for males than for females" since (at least as of 1973) male

status within both the familial and outside social contexts hinged heavily on a man's ability to be fully and successfully employable. Hypothesis 6 relating to the overall visibility of impairments is also taken to be self-evident, but the explanation for Hypothesis 7 reveals a wealth of commonsensical assumptions about the relationship between society's expectations of youth and the consequences of an impaired young person's failure to present a "body beautiful…body whole" (117). The logic operating here suggests that young people would reject one of their own for being a failure more readily than a member of an older generation would theirs, simply because slowing down in one's advanced years is taken to be a natural given.[26] Such a visual affront to the fantasy of the beautiful, vibrant youth would therefore present a constant challenge to smooth interpersonal interaction between a young person and their peers.

In addition to age groups and gender, the hypotheses suggested overall that attitudes toward visible impairments would also vary between income levels. While lower classes were expected to be more familiar with hard labor, and therefore injury, the upper and middle, educated classes were expected to experience increased frustration when confronted with an inability to control their own health situation. In this case, the "passive acceptance of natural phenomena" that lower classes were forced into acquiring through their lessened circumstances would prove here to be a blessing instead of a curse (118). The over-arching expectation at the outset of the study was that as visibility of impairment increases, so too would the difficulty of smooth interpersonal interactions across all social contexts.

[26] This is a point that Wendell (1996) also tries to make. When describing her own cognitive symptoms arising from CFS she notes that it doesn't register as a symptom, because "this is a weakness to which many of us who are over forty-five are susceptible" (3). She then goes on to argue that, in any case, society should attend more fully to 'disabilities' because anyone who lives into advanced age will necessarily stand a greater chance of experiencing disability.

But except where the impairment involved a grave reduction in the mechanical faculties of communication, the results of the study revealed that the obverse of the initial hypotheses was true. Where the ambiguity of health status increased, so too did the breakdown in interpersonal relationships among all social contexts, and across ages, genders, and income levels. Where impairment was judged as a measure of the degree to which employment was affected by physical limitations, the study did prove that impairment had a decided effect on interpersonal relations – however it was the "opposite of that predicted by the hypothesis. Overall, data indicated that the *more severely impaired* are likely to have *better* interpersonal relations than are the less severely impaired." [27]

Of course, "better" is in the eye of the beholder, and many visibly disabled people have objected to being routinely forced into the role of 'the disabled' for the comfort and convenience of the non-disabled. For the sociologists conducting the study, the "better" is derived from the fact that "norms attendant the sick and/or disabled role become clearly applicable" for interlocutors in social situations, in stark contrast to the disrupted, fraught social encounters that the less visibly impaired are constantly subjected to. In musing the reasons for why this might be so, the study offers two possible scenarios: that the less visibly disabled are more "psychologically disturbed," and therefore difficult, or that the absence of visual cues results in a failure to evoke "sympathetic and humanitarian responses from others" (119).

The results stated in their conclusion indicate that the latter possibility is the more probable one. For Hypothesis 1, as long as the impaired person retained some basic,

[27] Ibid., 119. Emphasis original.

functional abilities for communication, their unambiguous disabled status resulted in overall positive interpersonal relationships as measured against "loss of communication skills, loss of employment skills, and impairment of sexual functioning." The conclusion of Hypothesis 4, relating employment status and social interaction, found that for friendships and casual acquaintances employability was still a strong contributing factor, especially for men. However, for the conjugal or family relationships, a person unable to work actually had *better* family and spousal relationships than did those who were unemployed yet could be employed in a work situation, presumably with accommodations. Once again the researchers use the language of roles and clarity – "Apparently, clear-cut functional limitations call forth sympathetic responses from family members, leading perhaps to a family organization in which one member is cast into the disabled role" (120).

By this point in the study, the answers to Hypothesis 6 & 7 are already becoming clear. The role of the visibly, 'totally disabled' person is the safest one to inhabit when in social situations, whether it be with spouse, family, friends, or coworkers. Even spouses with impaired sexual function seemed to enjoy a better family life than those who were physically impaired, but yet still retained some sexual abilities. The non-visibility of impairments, with visibility here broadly defined as the presence of "equipment for ambulation or muscular support," was the strongest predictor of social strife for the disabled. Contrary to expectations, this was still true even of the younger age groups: "the visibly impaired tended to get along better in interpersonal relations than did the non-visibly impaired" (122).

In sum, this research supports the assertion that in the absence of a mitigating circumstance of being ‘obviously’ disabled, a person is qualified in the social realm to be morally judged according to how well they conform to a dizzying array of cultural and aesthetic expectations attendant to all would-be productive citizens of the Western world: the physically active, economically strong, masculine provider (Charmaz 1994; Shriver & Waskul 2006; Gilmore 1990; Gutmann 1997); the do-everything feminist Super-Mom who also somehow makes time for herself, despite her demanding career (Wendell 1996:4); the hard-partying, yet stubbornly exuberant and virile young person who works their way full-time through their equally full-time studies; just to name a few familiar archetypes. Everyone is fit. Everyone manages their time well (Martin 1994; 2009).

Violating these expectations arouses suspicion and disbelief, especially when there is a claim of disability that does not seem visibly justified. Such claims risk being undermined not only in everyday social situations, but also by the discourse generated within realms of medical or critical scholarly expertise. These alternatives to embodied authority pose a unique level of challenge inasmuch as an individual is forced to engage with it, or if potential access to legitimating discourses are threatened to be blocked in some way by it. In other words, it is unavoidable.

CHAPTER 2
Contesting Illness

> The insistence that one group of people should be entrusted with the characterization of another group of people, and the allegation of the obvious superiority of the "experts'" criteria of group membership to those formulated by members of the group in question on the basis of their lived experiences are the epitome of oppression, and perhaps even an ostensive definition of it. [28]

Claims that threaten or destroy the legitimacy of another's suffering can certainly spring from everyday banal social interactions, the dynamics of which will be explored in greater detail in the final chapter of this paper. But when unequal power relations are added to the mix, the potency of oppression takes on a new dimension. This chapter is about the ways that two species of experts, medical doctors and critical scholars, have woven alternative narratives which, in some cases by design and some cases not, challenge the authority of those who make embodied claims about their own suffering; these embodied claims are called "illness narratives" which allow others to "study the patient's illness experience and illness world as a social reality apart from the conception

[28] Davis, "Invisible disabilities," 179.

and definition of illness as formulated by biomedicine" (Kleinman 1988; Hydén 1997:49). [29]

In his article, "Illness and narrative," Hydén provides a useful overview of this use of the narrative concept within medical contexts and its changing meaning within the social science fields. Narrative, for medical sociology, proliferated in the 1980s and 1990s. The concept is most generally defined as a way of conveying life histories and especially the experience of a change over time – such as the development of an illness – at the most basic level it is defined as having a beginning, middle, and end. At first, physicians were encouraged to pay attention to patient narratives to listen for clues which would enable them to parse together a diagnostic hypothesis; narratives were also a way that doctors could supposedly 'read' a patient as if they were a text. To take it even a step further, narratives were also used to look into how doctors were constructing the patient as social reality. Finally, the concept of the 'narrative' progressed to signifying the ways in which people make sense of their life socially.

The ways that narrative has been deployed in biomedical encounters and in critical scholarship can be illustrated by comparing and contrasting two texts, each written by experts in their respective fields. *Narrative Medicine: Honoring the Stories of Illness* was written by a medical doctor with training in literary theory, and *Under the Medical Gaze: Facts and Fiction about Chronic Pain*, was written by an anthropologist, also savvy in literary theory, who made her personal illness narrative into the auto-ethnography centering her analysis. By scrutinizing their methodologies, assumptions, and political proclivities, we might piece together how these alternative narratives are

[29] For a particularly interesting example of an illness narrative, see Anne Fadiman, *The Spirit Catches You and You Fall Down* (New York: Noonday, 1997).

constructed, and in turn, the different ways that they challenge the authoritative voice of the sufferer.

A Physician's Narrative

As discussed earlier, chronic illnesses do not meet our expectations in several different ways: those disabled by them do not outwardly appear as we are accustomed to seeing the stigmatized 'handicapped;' rather than a consistent state of blindness, paralysis, or the like, many chronic illnesses are by nature ever-changing and cycle from a worsened state into a remission state; they are not a transient sickness to be cured yet also not a fatal illness to attend. Neither the possible causes of contested chronic illnesses nor their diagnostic criteria enjoy epidemiological consensus, and thus medical opinion on the veracity of these illnesses can vary from doctor to doctor. They guarantee eternally frustrated medical providers, who far from being able to sweep in and restore health, are continually confronted with Normal or Inconclusive lab results and a stubbornly plaintive patient. Kleinman (1988) sums it up nicely:

> The upshot is that practitioners, trained to think of 'real' disease entities, with natural histories and precise outcomes, find chronic illness messy and threatening. They have been taught to regard with suspicion patients' illness narratives and causal beliefs. The form of those narratives and explanations may indicate a morbid process; the content may lead them astray (4).

When their diagnostic strategies do not bring forth results that correlate with the reported suffering of the patient, many physicians decide that the problem must be a psychological one, since depression can cause or worsen common complaints like pain or poor sleep. The patient has reported 'serious complaints,' but the doctor now knows that the complaint is not 'serious.' Therefore, the patient diagnosed with a chronic illness suffers doubly in that they are told that they likely have an incurable, barely treatable condition, but should not be overly devastated because it 'might' go away, and after all, they won't die from it.

Even if one were to finally locate a doctor willing to take their symptoms seriously, there is always the future risk that any change in care providers might result in a skeptical doctor who may disagree with the diagnosis, refuse to consider it biomedically valid, and potentially withhold any treatment that the patient may have been receiving from the diagnosing physician. The potential for misdiagnosis is also very high, as later developments may reveal another primary cause that the doctor may have missed. In addition to overlapping symptoms between chronic illnesses, some criteria include the diagnosis of another chronic illness! [30] Because the strategy for treatment of most chronic illnesses focuses on the reduction of symptoms, it often may not make considerable difference which label physicians choose, so long as they work with the patient on strategies to keep the suffering at manageable levels.

But the ability to attend to patients' suffering is predicated upon the notion that a doctor will keep an open mind and listen to what they have to say. This is what Rita

[30] According to the CDC, Fibromyalgia is often co-morbid with Chronic Fatigue Syndrome. Adding to the confusion, the two have many overlapping symptoms and are among a group of very similar diagnoses of exclusion.

Charon, MD., proposes that doctors do. An internist also trained in literary theory, Charon espouses what she calls "narrative medicine." The term refers to "a clinical practice informed by the theory and practice of reading, writing, telling, and receiving of stories"(viii). She believes that training medical students in literary theory and methodologies can help to instill in them traits like humility, accountability, and empathy. In her book, *Narrative Medicine: Honoring the Stories of Illness*, she lays out a vision for narratively-informed doctors, frequently calling upon them to "bear witness to the patients' suffering."

By "bearing witness" she means allowing the patient to have a sufficient amount of the doctor's time whereby they can sit and listen to the stories the patients tell of their experiences of illness. She lists bearing witness as one of three essential literary skills, along with close reading, and reflective writing. In her accounting, close reading sounds very much like active listening; by being versed in the various ways of reading texts, and applying them to the narratives shared by patients, doctors can 'see' inside a patient's understanding of their own suffering. Reflective writing refers to methods of recording information within the clinical context, and can also refer to the diaries that medical students are encouraged to keep to enable them to reflect upon their experiences with patients.

In explaining how she came to practice narrative medicine, Charon relates an early lesson that she learned when doing her first bit of reflective writing. She describes an encounter with a possible case of chronic illness, and it provides a fascinating glimpse into her viewpoint as an attending physician. She describes her patient, "Luz," as an attractive young woman of twenty-one. Luz had come to her several times complaining

of headaches which Charon “had not considered terribly worrisome;” she was prescribed acetaminophen. Finally one day, Luz appeared at the doctor’s office without an appointment, asking Charon to sign a disability form for her. “I remembered being irritated,” she writes, “not only that she thought she deserved disability on such slim clinical grounds but that she would appear, without an appointment, and expect me to make time to fill out the form" (5). Hurried, busy, and late for a meeting, the doctor complied.

The incident later bothered her because she had acted “brusquely and dismissively without knowing [Luz’s] situation.” Not knowing the real reasons behind Luz’s sudden appearance, Charon then decided to write reflectively about the experience, filling in the missing details with her own work of fiction. In this literary exercise, she wrote from the perspective of Luz, who (in her story) was an aspiring model hoping to move to Manhattan in the pursuit of a career. The disability payments would support her as she looked for a job. In reality, Luz *did* need to move to Manhattan, but her situation was far from glamorous. She wanted desperately to move her sisters out of their sexually abusive home and set up a new, safe place for them. Though her imagination hadn’t been very close to the mark, Charon explains that this narrative exercise had succeeded in motivating her to learn of "[Luz’s] true plight instead of blaming her or suspecting her of malingering"(6). The effort of the storytelling exercise had helped her "take care of the patient by bringing me to her side, seeking to understand her behavior, taking seriously her situation, and gaining access to the unsaid knowledge I had already developed of her strengths and desires."

Perhaps the most noteworthy part of this anecdote is that Charon never again referred to the headaches or even the possibility that Luz might have been suffering on a debilitating level. In her mind, she had failed Luz as a doctor not because she had dismissed her patient's symptoms, but because she hadn't cared enough for the patient to invest the effort required to find out what was 'really' going on. The headaches must have been dismissed either as an exaggeration on Luz's part, or as simply a byproduct of Luz's abusive past, but Charon never elaborates. Nowhere does she wonder why Luz would attempt to support herself and four sisters on a paltry disability payment. Nor does she mull over the fact that an attractive twenty-one year old, apparently beautiful enough to be a model, was asking to be labeled as disabled. Surely a job would have provided more income than government payments? The question of her would-be 'disabled' status is never again addressed, her attempted 'fraud' glossed over. Clearly, 'narrative medicine' is not what it initially appeared to be.

Despite her claims that narratives are an intersubjective experience, beneficial to all involved, an examination of Charon's terminology reveals that a somewhat insidious and persistent partition exists between doctor and patient. Dichotomies of sick/well, doctors/patients, clinicians/patients, sick person/professional proliferate her prose; she even refers to "we, the healthy" when addressing her paragraphs primarily to fellow doctors (97). Importantly, she sees narrative medicine as a form of therapy for *doctors* who are constantly confronted with the suffering of others, because, she explains, "many health professionals are uncomfortable around emotion" (98). This begs the question: Just who is the practice of 'narrative medicine' primarily supposed to help? She insists that doctors must use narrative medicine as best they can to approach the realm of the patient,

because even their conception of time is different: “health professionals have an urgent need to examine and make at least imaginative sense of how patients might experience time” (121). They must “imagine the times of others” and “envision the inner experience of its passage” (122). What is more, she cautions, patients do not have a full understanding of their own mortality.

Using Charon's framework, then, doctors and patients are profoundly at odds. It sounds so promising, initially: “[a]ny effort to provide health care begins by bestowing attention on the patient” (132). But quickly devolves into something else: “We clinicians donate ourselves as meaning-making vessels to the patient who tells of his or her situation; we act almost as ventriloquists to give voice to that which the patient emits.” Herself a third-generation M.D., she dutifully reminds doctors that “our bestowing of the gift of attention, or presence, incurs in us both responsibilities toward the other and transformations within the self” (134). Aren't we lucky?

In this formulation of narrative the dictum of ‘honor the stories of illness’ appears at first to be a more or less straightforward call for doctors to spend more time with patients, and to avoid discounting patient voices as they attempt to share their own illness narratives with their doctor. This would theoretically have therapeutic effects for the patient, and also has the added incentive of providing possible clues to the diagnosis. Alas, this does not seem to be the case. Charon warns that: “It is folly to expect that a sick person can tell a professional what the matter is. If some oral narratives of illness sound chronological, well organized, and coherent, it is probably because the patient wrote an outline and rehearsed its performance” (99). What happened to honoring the stories of illness?

Indeed, as the book proceeds, an altogether eerier version of the subtitle suggests itself: the 'honoring' in 'honoring the stories of illness' *really* means bestowing the gift of a physician's attention. To risk putting it cynically, physicians will proceed to magnanimously deploy their superior narrative and diagnostic skills to pluck hapless patients from the depths of their naiveté and deposit them into the light of truth. "The listener, or reader, is not a passive receptacle. Instead he or she is shaping, questing, asking, probing, forming hypotheses, trying hypotheses, delving into possible interpretations, looking for clues everywhere, listening for the authentic voice" (58). Not only is it a responsibility to engage in this "probing," "meaning-making," and "imagining," it is also a duty and privilege for the professional clinician: "Knowing something about the body grants us the license to near another. It grants us admission to a proximity to the self of the other, and, by reflection, of ourselves" (xii).

I found the effect of reading this text altogether claustrophobic. I am not sure which is worse, the detached, dismissive doctor, or one engaged in Charon's brand of narrative medicine. The impulse to annex what is generally seen as the purview of a psychiatrist or psychologist and then graft it onto clinical practice is first of all alarming to me as a patient, and second of all it strikes me as move to grasp onto even more power and authority. This idea was put forward to be an *improvement* upon doctor-patient relations, but I suspect that it merely opens up yet another space for doctors to engage in "delegitimation" (Ware 1992; Kleinman 1992). Many, many studies and research articles have interviewed patients with chronic illnesses and have catalogued their war stories of delegitimation by physicians (Prins et al. 2000; Dawes 1991; Clarke & James 2003;

Åsbring & Narvanen 2003; Cooper 1997; Deale & Wessely 2001; Shriver & Waskul 2006). But here is a recent example from my own bit of research:

> I know I have M.E - I've been sick since I was 8yrs old and I'm now 20. The docs tried to say I had PTSD (Post-traumatic Stress Disorder) [and] they even accused my mum of abusing me....the medical profs have no idea what they're doing!!!!

In the absence of biomedical 'proof,' frustrated doctors move to shuttle patients off to the psychiatrist, thinking that their complaints must be psychosocial in origin (Chaudhuri & Behan 2004; Evengård & Komaroff 1999). This dynamic is perhaps unsurprising, but what *is* surprising is a disturbing convergence: the move to attribute psychosocial causes to embodied suffering also pervades critical feminist discourses - the very projects meant to critique the unequal power relations between doctor and patient. The next section examines just such a project.

The Critical Scholarship Narrative

In the mid-1990s, anthropologist Susan Greenhalgh began to experience increased pain. Already diagnosed with psoriatic arthritis, she became alarmed by the new tenacity and intensity of her chronic pain. Hearing of a specialist a few states away, she travelled

to seek out the opinion of a rheumatologist. This first encounter with her new physician inaugurated almost 8 months of stress, wildly fluctuating symptoms, and reactions to heavy medications –all of which ultimately converged into what she describes as a near-nervous breakdown. This rheumatologist, significantly a *male* rheumatologist, was convinced that Greenhalgh had a rare (as it was thought then) and little-known chronic illness called Fibromyalgia. This illness had no cure, nor treatments for an underlying cause, and the prognosis was not an encouraging one, to say the least. And she would likely have it for the rest of her life. Her ability to concentrate and perform her roles as scholar and professor would likely decline, and her only hope was to trust in her doctor completely. Faced with this devastating development, Greenhalgh dealt with it the best way she knew how: as a scholar. She took meticulous notes, keeping records of her interactions with the doctor during her appointments and of their written and phone correspondence. She also maintained a detailed a diary of her daily struggles with this mysterious new illness. These materials formed the base of her autoethnography.

Despite some internal misgivings, over the next several months she flew out multiple times to consult with her new doctor, following his advice and recommendations. In order to treat her 'Fibromyalgia' he prescribed a cocktail of very strong drugs, which included an anti-inflammatory the side effects of which were known to cause headaches and mental fog. When she began to experience persistent headaches and maddening cognitive effects, the doctor instead attributed them to her 'Fibromyalgia' and recommended that she also take over the counter headache medicine. In addition, when she was given sleeping medications, which had the potential for addiction, she became increasingly disturbed as she grew to feel that she could no longer sleep without

them. Her doctor, however, was unperturbed. Apart from this new medication regime, he counseled her to cut out any activities that might threaten to exacerbate her symptoms, and this resulted in so many serious restrictions on her life that she felt as if her very identity was slipping away.

In misery and desperation, through the haze of side effects and stress, she was able to reach out to another rheumatologist for a second opinion. Fortunately for Greenhalgh this rheumatologist was a woman. She did not concur with the diagnosis of Fibromyalgia, and moreover, she considered such an extreme drug therapy far out of the mainstream of medical practices. In her opinion, instead of 'Fibromyalgia,' what Greenhalgh suffered from was her psoriatic arthritis – and the effects of "psychosocial pressure" to be a compliant woman in the face of a patriarchal, heterosexual male doctor. Empowered and finally relieved of the potent drug side effects, she returned to her original doctor and confronted him with her new realization. In an especially interesting and dramatic part of the book, she relates what happened as she delivered a written statement, in person, to her doctor, which laid out the conclusions she had come to regarding his faulty diagnosis of Fibromyalgia. In her opinion, his all-encompassing belief in the correctness of his diagnosis had caused him to bolster his own opinion when his 'treatment' inadvertently replicated symptoms commonly attributed to Fibromyalgia. Perhaps predictably, she was met by an indignant and baffled response.

Driven by her negative experiences, Greenhalgh determined to write an auto-ethnography about it in the hopes that others would be helped by an account of her ordeal. She presents her story as a clear-cut case of an overbearing male doctor against a strong female scholar who eventually found her voice and told him 'No.' However, she

reaches beyond her own illness narrative to make a bold claim: 'Fibromyalgia' does not exist. It never has existed. Though the suffering that women experience is 'real,' Greenhalgh says, it springs from societal pressures and felt inequalities; these expressions of suffering are then medicalized and labeled 'Fibromyalgia.' "From witches to hysterics to fibromylagics, women have been harmed or incited to harm themselves for deviating from expected gender norms" (7). Therefore, in this construction, once a woman realizes as Greenhalgh did that her Fibromyalgia diagnosis is false, the mental oppression will be relieved and the physical suffering will fall away. But interestingly, she takes care to draw a line between chronic illness and "established chronic diseases [such] as arthritis, diabetes, hypertension, and heart disease." [31] Speaking directly to those "afflicted with the new chronic conditions of late-twentieth century civilization," she explains that, "Women desperate for someone to acknowledge and alleviate their suffering go to their doctors to name and ease their new pains. Professionally obligated to heal and motivated by humanitarian impulses, our doctors try to live up to our expectations" (3).

This anti-illness reification, or anti-biomedical discourse, has unfortunately been a common one within critical feminist scholarship. Contested illnesses by their precarity lend themselves readily to all manner of etiological schemes. As Goffman (1964) says, "the point where medical science must withdraw is the point where society can act most determinatively" (124). Particularly, the notion of the "mindful body" (Scheper-Hughes and Lock 1987) has provided an analytic space to attribute political and social causality to bodily suffering in ways that pose a strong challenge to illness narratives: "Sickness is not just...an unfortunate brush with nature. It is a form of communication - the language

[31] Greenhalgh is following medical nomenclature; "illness" is the experience of poor health, while "disease" is biomedically defined and labeled (i.e. legitimated).

of the organs - through which nature, society, and culture speak simultaneously" (DiGiacomo 1992:25). I rather agree with Susan DiGiacomo when she objects to this sort of project for enlightening the ill masses "that proposes, rather patronizingly, to instruct them (us) in the 'true' nature and sources of their affliction" (1992: 128).

But I don't wish to give the impression that I am discounting or condemning all of the valuable work done by feminist scholars; in fact, the very ethnographies that this analysis relies on as both a source of illness narrative and autoethnography were written by critically-informed feminist scholars. They recount how their political and theoretical commitments interacted with their experiences of illness in interesting ways. Susan DiGiacomo, an anthropologist and cancer survivor, relates how her experiences with Hodgkin's disease caused her to see some feminist scholarship in a different light. For example, in analyzing Susan Sontag's "Illness as Metaphor" (1978), she concludes that:

> It is not at all clear that the notion of illness as a 'coded metaphor' for social and economic dislocation would either further the theoretical aim of developing a critical medical anthropology capable of synthesizing cultural interpretation and political economy, or empower the ill. [32]

Susan Wendell, a CFS sufferer and also an anthropologist, offers a possible explanation as to why feminist scholarship has had difficulties conceptualizing the "negative body" (1996:166).

[32] DiGiacomo, "Metaphor as Illness...," 126.

> Because the Western tradition particularly devalued women's bodies and appropriated the authority to describe bodily experiences unique to women... in reaction to this tradition and its consequences, feminists have celebrated the body, emphasizing aspects of bodily experiences that are sources of pleasure, satisfaction, and feelings of connection. [33]

Even though these reactions were valuable, she explains, this tendency to focus on the good body has diverted focus away from the bodies that are "a source of frustration, suffering and even torment" (167). This has the tendency to alienate disabled women, who cannot participate in this picture of the ideal female "any more than they can in the idealized images of sexist society." It is this effect of alienation that concerns me about Susan Greenhalgh's authoethnography.

As an expert and a patient, Greenhalgh's version of events enjoy unprecedented authority throughout her account. A quick internet search for books on 'Fibromyalgia' will display her book in the results. This, together with the title, *Under the Medical Gaze: Facts and Fiction of Chronic Pain,* may lead people newly diagnosed with Fibromyalgia or other chronic, contested illnesses to believe her book is about something that it is not. It is not a source of unbiased information, nor is it a self-help book in a traditional sense. Crucially, the book completely also ignores the plight of men, who also suffer from and are diagnosed with chronic illnesses such as Gulf War Syndrome. In describing FMS in

[33] Wendell, *The Rejected Body*, 167.

such exclusively female terms, what space does that leave for a man trying to make sense of his own suffering?

To use “chronic pain” as shorthand for all the suffering associated with chronic illnesses does all chronic illness sufferers an injustice. And as one interlocutor told me, a diagnosis of chronic pain is fairly useless: "[it] means nothing to me apart from describing how I feel!" But even there it also fails. Pain is only a shade in the spectrum of discomforting sensations which can include various total or partial bodily weaknesses, stiffness, inability to concentrate or remember things, inability to maintain a comfortable body temperature, non-restorative sleep, post-exertional malaise, and others. And in the long-term, chronic pain alone can easily result in a sedentary lifestyle which eventually contributes to weight gain, deleterious effects on muscle strength, and reduction in overall stamina. It is not surprising that this embodied experience of struggling to proceed with the everyday life activities adds emotional stresses including but certainly not limited to frustration, anger, denial, hopelessness, guilt, and shame.

Though Greenhalgh describes the process of going through the emotional turmoil of adjusting to constraints on her life activities, according to her own illness narrative, these ‘constraints’ were imposed *a priori* and not as a result of experiencing debilitating suffering. Greenhalgh also spends too little time attending to her own advantaged position and how it may have affected both her experiences of illness and the 'lessons' which she derived from them. Her not inconsiderable amount of social and cultural capital afforded her a level of physician access above and beyond the average patient experience. She describes “an unusually high-contact medical relationship” that included office visits each “ranging from two to five hours in length” as well as “twenty-two

phone conversations running perhaps from fifteen to forty-five minutes." By way of contrast, according to the National Ambulatory Medical Care Survey, Americans have, on average, about 13 minutes with their doctor.

In addition, the experience of being immediately diagnosed and treated by an enthusiastic specialist is a novel one. In the mid 1990s, a majority of doctors remained skeptical of Fibromyalgia as a valid diagnosis, even after the American College of Rheumatology released its clinical criteria in 1990. Though research has proceeded apace and awareness has improved markedly within the past two decades, a glance at any online community of chronically ill people, especially those with Fibromyalgia, will still reveal a multitude of 'war stories' – tales of seemingly endless appointments, 'normal' test results, condescending (and yes, often patriarchal) doctors, and referrals to a psychiatrist (Barker 2008). Some have gone for years without any relief from symptoms because doctors have refused to accept the legitimacy of their suffering.

Purportedly speaking for the "plight of the ill," Greenhalgh insists that one of her goals was to "alert patients who are unfamiliar with social studies of biomedicine to the power dynamics in their medical encounters" (7). I suggest that this reflects a fundamental misconception about the common American's experience of chronic illness and diagnosis. In any case, one need not be familiar with social studies of biomedicine to be aware of the strident power dynamics often inherent in the doctor-patient encounter.

Greenhalgh's overall logic, therefore, seems to be inexplicably backwards: "A sense that one's body falls within the range of what is 'normal' is worth fighting for, for once that identity is 'spoiled' by a biomedical label, one is subject to all the problems of

the stigmatized – from discrediting and discrimination by others to feelings of shame and inferiority that come from within" (35). By virtue of the contested nature of chronic illnesses, the most common experience is the direct opposite. A biomedical label is an affirmation of the *lived experience* of not-being-normal, despite constant outside insistence of normalcy. As Kleinman has observed, "The way of the specialist diagnostician, which is not to credit the patient's subjective account until it can be quantified and therefore rendered more 'objective,' can make a shambles of the care of the chronically ill." [34]

In sum, through privileging her own illness narrative in the formation of broader generalizations about chronic illness, Greenhalgh's argument runs the risk of alienating people who really are suffering with an FMS that informs their experience of their bodies in a way that her personal experience did not. She often uses the word 'narrative' in various ways depending upon the theory or body of literature she is referring to, but does not sufficiently attend to the particularities of her *own* narrative; her experience is only one possible narrative among many. Though she takes great pains to insist that doctors, despite their claims to objectivity, are also engaged in their own storytelling, she nevertheless seems to buy into their case at least part of the time.

And though she accuses doctors of behaving as if biomedical truths are the only truths, she must also on some level agree; she seems to make the underlying assumption that because medical science has yet to unravel the etiological mysteries of contested chronic illnesses, they simply must not biomedically exist in the first place. Therefore, if medical science demurs from bestowing upon chronic illness a full legitimacy, the truth

[34] Kleinman, 17.

of the matter must lie in psychosocial or sociopolitical constructs. Without invalidating the central accomplishments of her exploration of gender and power within the medical context, I believe that Greenhalgh's book makes potentially damaging over-generalizations about the nature of chronic illnesses. Such generalizations, along with the delegitmation of suffering by medical doctors, each present sufferers with yet another source of stigma to manage, another battleground on which to fight for the authority to define their own identities. The effect of these struggles on the everyday lives of sufferers is the theme of the third and final chapter.

CHAPTER 3
Another Closet

This thesis has so far been concerned with laying the groundwork necessary to elucidate a conceptual framework that is the main thrust of my argument: that people with non-apparent disabilities are forced to live with crises of identity, constant threats of delegitimation, and with bodies that behave outside of social norms but that do not at first betray themselves as such. Furthermore, this mode of constant body and identity management that they are forced to function in is distinct both from understandings of the 'healthy' mode of functioning, and also of the dominant paradigms used to describe the 'disabled' mode of functioning. Therefore they can be said to inhabit a third space of being. Perhaps it could be called 'Gimp' space, but I am not expressly engaged in a project of politicization. Instead, the term is intended to conjure forth impressions of another conceptual third space of being - the Queer space.

Queer theory allows discussions to escape from a "binarized identity" (Sedgwick 1990:2) imposed from without - significantly, between that of heterosexual and it's obverse, homosexual. And as Faubion (2010) notes, “the closet is not a preserve unique to the homosexual. It is the safehouse of anyone suffering the accusation of deviance or the burden of the danger of status debasement” (15).Though Sedgwick herself never used the term "queer closet" in her foundational work *Epistemology of the Closet*, it came to be an oft-used term in queer studies. [35] Following this tendency, I use the phrase 'the queer

[35] Sedgwick calls attention to this point in the preface to the updated 2008 publication of *Epistemology of the Closet*.

closet' or the 'logic of the queer closet' as a framework to assist in illuminating the ways that people with non-apparent disabilities go about their lives. In order to effect this synthesis, I appeal to Irving Goffman's most clear and impactful works, *The Presentation of Self in Everyday Life* (1959) and his later work *Stigma: Notes on the Management of Spoiled Identity* (1963).

Before continuing any further – it is important to define carefully what I do *not* mean by invoking the discourse of the closet. I do not in any way mean to make the suggestion, one that resides in the not-that-distant past, that non-heteronormativity should be pathologized or medicalized in any sense. Nor am I making the case that queer identities are a disability. There are certainly limitations to the analogy, and I will take a moment to explore them here. First, it must be said that this way of speaking about illness and disability is not an innovation - other scholars have engaged in projects of "queering disability" (Claire 1999; Samuels 2003; McRuer 2003) and using the one to speak about the other (Swain & Cameron 1999; Shakespeare 1996; Garland-Thompson 1997; Wendell 1996). And second, I acknowledge that "such analogies often create and rely on artificial dichotomies that not only produce inequality between the terms of comparison but exclude or elide anomalous experiences that do not fit easily within their terms" (Samuels 2003:235). I have tried my best to avoid this.

A Third Space

Goffman (1963) describes two paths of stigma: the discredited, and the discreditable. The discredited is always already exposed, and therefore passing or closetedness is not possible for them. The discreditable, however, do not appear as they otherwise are. Thus we can easily locate those with non-apparent disabilities within the realm of the discreditable. There are two identities at play, one "virtual" and the other, "actual." Virtual is what persons appear to others to be, and actual is what they really are. It is the discrepancy between these two that potentially generates stigma (3). Because individuals are presumed to be healthy (and heterosexual) unless proven otherwise (Swain & Cameron 1999) it is here that we can pinpoint the closet.

The most useful way to explore the dynamics of the closet is to follow Sedgwick's discussion of the Biblical story of Esther.[36] She uses it to differentiate the features of queer outing from another outing – that of Esther's Jewish racial identity. In so doing, the logics of the queer closet are made explicit. The first distinguishing feature is that, once Esther outed herself as Jewish, her husband did not question it. There were no appeals made to someone else's expertise, no institutional sanctions were required. He doesn't suggest that she's just "going through a phase, or just angry at Gentiles, or could change if she only loved him enough to get counseling" (79).

Outing oneself to close friends or family can always backfire, but without at least an attempt at gathering a support system, it makes coming out to others in the wider social circle that much harder. If my own father won't believe me, who will? If my own

[36] *Epistemology of the Closet* (1990), 79-82.

spouse thinks I'm making it up, why should I expect my boss not to think so? And family members should not be presumed to be a source of support for the disabled person. Considering that they may constantly endure hearing their loved one complain of symptoms, or repeatedly be forced to deal with disruptions to the otherwise smooth operation of life because of that family member's health failing, it's not surprising that people report failed marriages and strained family relationships. "In spite of this evidence for everyday beliefs about stigma and familiarity, one must go on to see that familiarity need not reduce contempt" (Goffman 1963:53). Then again, outing to some family members may work, but for the good of the family unit it might be expected that the knowledge is hidden from others in the family. Then the maintenance of the closet becomes a *family affair*, as awkward questions must be anticipated, covered over or fielded. Shame and guilt can arise at anytime. Shame for being a social pariah, and guilt that a loved one has to defend you to others because of it.

An additional problem is that, if one has successfully managed to out oneself, even having provided answers to any instant objections that arose, there is no guarantee that this 'out' status will stick. Closets are stubborn. Even if you've come out to someone, they can either forget, silently refuse to really believe, or loudly question the veracity of your claims. Though 'passing' would seem to spare someone the grief of the outing process, people with non-apparent disabilities have no choice in the matter. This is a unique relationship vis-à-vis the closet: rather than being able to seek refuge in it, people are constantly trying to escape it. The alternative is to give a false impression of being able-bodied, and the social consequences for failing to adhere to someone's expectations can be very grave indeed. But even announcing one's disability may not be enough;

because of the element of non-visibility, the impressions one is *giving* and the impressions one is *giving off* do not appear to validate each other (Goffman 1963:2).

How would one give off the impression that they are indeed disabled? By adhering to social norms and expectations: wheelchairs, white canes, guide dogs, etc. Failing to do so invites suspicion. “Knowing that the individual is likely to present himself in a light that is favorable to him, the others may divide what they witness into two parts; a part that is relatively easy for the individual to manipulate at will, being chiefly his verbal assertions, and a part in regard to which he seems to have little concern or control, being chiefly derived from the expressions he gives off” (Goffman 1959:7). There is a paradox involved here. On the one hand, proclaiming oneself to be disabled is a powerfully stigmatic claim; why would anyone do this? On the other, a person is implicitly asking to be forgiven social sins; they are trying to qualify for empathy – take on a role that they do not appear to fill. Claiming a stigma then, becomes a “favorable” light.

Returning to the story of Esther - a second observation that Sedgwick makes is that Esther's husband is completely taken by surprise by her revelation. Not only that, but Esther seems fully confident that she has successfully managed her stigmatizing information up to that point. Here the comparison with the queer closet can still hold depending upon the context, but not as tightly. While it is true that in "mixed interactions" (Goffman 1963:12) people never can be sure who knows about their health status, it may not matter because they are not always able to control their comportment in such a way that their fatigue or pain is undetectable. Here again, though, the stubborn closet returns – polite company does not point out someone's difficulties, and in any case,

it doesn't seem that people pay much attention to such indications. After all, they could simply be written off as everyday ordinary tiredness or aches and pains. And frankly, someone's failed health is perhaps not as salacious or exciting as their sexuality or gender identity. It may be impossible to predict which among the gathered company remembers or even took it seriously, if you've outed yourself to them in the past.

In more intimate settings, such as among family and close friends, the above distinctions may no longer hold. It is much easier to discount the outing of a colleague or acquaintance than it is one's own daughter, father, spouse, etc. Outing takes on new consequences. This is a third observation in the story of Esther: she seems unconcerned at the effect her outing might have on her husband; the risk is chiefly to herself, and her people. But it is entirely possible to be stigmatized by association. The 'sufferer' is not the only one who suffers. As with coming out in the traditional sense, parents and close friends can be devastated. It can mar the closest of relationships. And the impulse to try and normalize a loved one is almost certainly the first result; on a certain level this is understandable. While it's true that they may want to avoid any guilt or taint by association, it's more likely that a loved one instinctively, if not in any coherent form, realizes that stigma, judgment, and misery can come out of this identity 'choice.'

Thus, trying to bring the stigmatized person back into the fold is a desire that dies hard. Years can go by and your uncle might still ask if you're over it yet. Are you sure you've tried acupuncture? As with effects of queer outing, similar feelings or fears of loss that people experience with a 'disability' outing are also at play. Am I never going to have grandchildren? Is my son or daughter doomed to never have a serious relationship? Could I have done something to prevent this? Did I do something to bring this about? These

fears are then often projected onto the other person: If your faith was stronger, you wouldn't be ill. Have you been to a psychiatrist? What do they have to say? Perhaps you'll get over it soon. Why are you seeking attention like this? Have you tried acupuncture?

But for Esther, she has a base of support through her identity; she "knows who her people are." But the disabled have to scramble; always they must "with difficulty and always belatedly to patch together from fragments a community, a usable heritage, a politics of survival or resistance" (Sedgwick 1990:81). Though there are pride parades which make spaces available so that people can finally come together to celebrate their non-heteronormative identities, I cannot imagine such a thing as a chronic illness pride parade. Without even addressing how ludicrous it would be to celebrate feeling miserable most of the time, it would be impossible to schedule a time and date that would be accessible for everyone. Because the nature of chronic illness is that it is completely unpredictable, scheduling political events would likely result in more guilt and more shame for those who couldn't attend. The rest would simply be miserable, as they would be unable to manage potential symptoms through control of their own environments in ways that they could at home.

The final zone of overlap between queer closets and disabled ones can be illustrated by Sedgwick's observation that Esther did not, at any time, assume her husband was a closeted Jewish person. The possibility of that had simply never occurred to her. Contrast this with the havoc that closeted homophobics often wreak upon the outed homosexual. Here, too, there is room for comparison. It is so important to remember that the experiences of illness vary on an individualized basis. There is nothing

worse than being betrayed by one's 'own kind.' I have a chronic illness, too, and yet I could still make that game, finish that article, meet that deadline. Why couldn't you? Acupuncture has worked great for me; have you tried it yet?

Special Insights, Fieldwork Results

So far the above discussion has treated the experiences of closetedness in an way abstract enough to encompass most, if not all, of those who live with non-apparent disabilities. However, I want to move beyond the general to a few particular instances. There are innumerable facets to explore at the juncture of embodied experience and the mechanisms of social friction, and it would be impossible to describe them all. But there are two unique experiences that are so different from my own that I wanted to seek out the voices of a few who could enlighten me. Specifically, 1) the experience of being a man and non-apparent disabled, and 2) the experience of being *doubly* closeted: possessing both a queer identity and a disabled one.

My first key informant, who I will call 'Tim,' is an African American man in his late 30s. He and his partner, who is white, along with their three young biracial children, have been living together for several years. Though she was recently able to complete her college education, both of them struggle at low-wage jobs to keep the family above the poverty line; they have not gotten married in part because they would lose the government benefits that help keep the family afloat. His industrial job requires a lot of

heavy lifting and other strenuous activities. He told me that he once tried to calculate the average amount of weight that he had to lift or carry at work on a daily basis - it was in the thousands of pounds. Pain and fatigue has drastically reduced his ability to work. And recently, he started experiencing strange symptoms like pain and tingling in his hands and feet.

Forced to finally deal with these problems, when he couldn't push through it anymore, he paid out of pocket to see a doctor (the family does not have insurance). He was diagnosed with Lupus. Even though it isn't a 'contested' illness, and potentially poses serious continuing threats to his health, he has experienced resistance at both his job and in the doctor's office. When he approached his employer requesting reduced hours, citing his Lupus diagnosis, their response was, "Yeah, and?" Tim's doctor mistakenly diagnosed his hand pain as Carpal Tunnel Syndrome, and recommended surgery. Though it cost him thousands of dollars, Tim proceeded with the surgery. Later he learned that he'd developed Raynauds Syndrome, which causes tingling and pain in the hands and feet.

In talking with Tim, as he made his children pancakes, I could tell that he appreciated the opportunity to speak with someone who could speak the language of chronic illness. He didn't have to try and explain what Raynaud's was, and I could easily follow his stories about the various medications he'd tried. A quiet man, he seemed to become more engaged in the conversation the more I was able to offer indications that I understood where he was coming from. The experience of surprisingly overwhelming fatigue, the frustration of trying treatments that didn't work or just made things worse - all of these things I could understand.

Even though I experienced a lot of second-hand frustration hearing about his encounters with doctors, followed by the inevitable disillusionment with the medical profession, I felt honored that he was sharing his stories, and that I could in exchange provide some insights that I'd learned from my own experiences. Comparatively speaking, Tim is a 'young' chronically ill person; his diagnoses are a relatively new phenomenon for him. Through his stories I was reminded of some of my own first steps as a non-apparent disabled person. Although I don't know if Tim will apply for disability benefits, or keep trying to cling to a job, I do worry about his future health. Though it is completely nonsensical, public clinics don't want to treat Lupus until it becomes severe and life-threatening. It doesn't have to progress to that point, but it might without the proper treatment.

I was straight forward about my interest in his story, and asked him what it was like dealing with these new challenges as man with a family. Lupus is a chronic illness that can be just as unpredictable in severity as CFS or FMS. Dealing with ever-changing symptoms have understandably been a source of frustration and worry. He lamented his wild younger days; long before he met his current partner he had fathered other children. He shared with me his personal regrets and the shame he feels that he struggles to pay child support for these children from a prior relationship. There is also the additional guilt that paying towards the child support would mean putting a strain on the household finances. Once strong and carefree, now he has to try and hang on as best he can while also dealing with his reduced capabilities and confusing new symptoms.

The experience of men living with chronic illnesses is woefully understudied and under-theorized. Then again, men as a category seem to be under-theorized. According to

Gutmann (1997), as far as anthropology has been concerned, “Masculinity is either ignored or considered so much the norm that a separate inventory is unnecessary. Then, too, 'gender' often means women and not men” (403). Chronic illnesses are overwhelming gendered as female. And most discussions of chronic illnesses, contested or otherwise, begin by stating how much more prevalent it is in women. Many then seem to proceed as if women were the only ones affected. But the experiences of chronically ill men should not be minimized. Some work on masculinity has suggested that men's identities are not mapped primarily on their bodies as male, but instead are enacted: “there is a constantly recurring notion that real manhood is different from simply anatomical maleness, that it is not a natural condition that comes about spontaneously through biological maturation but rather is a precarious or artificial state that boys must win against powerful odds” (Gilmore 1990:11). Masculinity hinges on a man's ability to 'be a man' and to act like one.

Kathy Charmaz (1994) provides one of the few pieces of research on chronically ill men. Her study utilized interviews of around 40 men, and 40 women, and then compared the two for differences in how they dealt with the identity shifts that took place when they became chronically ill. Rather than focusing on long-term chronic illness, most of the discussion centers around men who had experienced a sudden break in their lives due to a serious illness, and then had to learn to live in altered circumstances. Men frequently referred to their break in health as akin to a “mid-life crisis” (272). Charmaz found that men, unlike women, more often strive to recapture their pre-illness selves, something that invariably results in failure and depression (279).

Men also did not feel the same relief when receiving the legitimacy of a diagnosis; instead, they "glossed over" the potential seriousness or meaning of their symptoms. Part of this difference can be accounted for by the fact that men "seldom had trouble in getting practitioners to attend to their developing symptoms" (273). Charmaz concludes that men try to either resurrect their former selves, or at least appear to be the same as they were; they see their illness as a battle to be won, and failing this, they may give up and fall into deep depression, ending up with a high risk of suicide. Considering the stakes, it is imperative that men's experiences of disabling illness do not continue to go unstudied.

The second illness narrative that I received came in the form of an online chat interview. A 21 year old white woman, NK [37] reached out to me on a social networking site. As both queer and disabled, she offered to provide her insights on how the closet analogy seemed to her, based upon her own experiences. She explained that her first 'outing' had been at 13 years old, when she revealed to her parents that she was queer. Her chronic illness outing happened later, but neither experience went well. She had presumed that the health revelation would be met with overwhelming support from her family, something that she had witnessed when an extended family member was diagnosed with cancer. This did not turn out to be the case. It might, in some respects, have been due to her medical history of having received psychiatric care. Her estranged biological father suffers with mental illness, as do many of those on his side of the family. And as fate would have it, in her early teen years she began to experience various behavioral and mental difficulties. Her exposure to the 'medical gaze' began young, so

[37] Not her screen name, or her real initials.

she had been receiving psychiatric treatment long before her FMS symptoms started. On the one hand, she was able to bypass the initial stage of having to prove her new symptoms were psychosocial in origin, but on the other, she had to learn all too quickly to deal with the impacts of illnesses that others don't see. “I missed so much school that I was taken to court for truancy, because I’d exceeded my number of absences that could be excused, even with a doctor’s note. I was put on two years of probation for that.”

Calmly, and matter-of-factly (or so it seemed to me, even though it was through online chat), [38] she added that she’d once been date raped, gotten pregnant, and then had a miscarriage. This experience added PTSD to her collection of things to manage. She also related how she had had to give up her dream of becoming a zookeeper. For a time she actually worked with zookeepers and loved it. It was doubly depressing when she'd had to finally quit because as far as she was concerned, the people she'd worked for at the zoo had essentially raised her. But alas, at the time she'd been dealing with cognitive symptoms similar to narcolepsy, and had no choice but to move on. “Zookeeping can literally get you killed, even if I was working with fairly manaegeable animals.”

Because of her long history of being on medications, she apparently was able to get access to new medications to help with her FMS symptoms. “They’d started experimenting with medicating me right out of the gate, so the actual diagnosis [of FMS] felt a bit superfluous by the time it came.” After she experienced a bad reaction to taking Lyrica, then the only medication marketed as a treatment for FMS, the doctor inexplicably doubled the dose. Her young life has been full to the brim with less than

[38] I remarked at how well spoken and concise her replies were, and she explained that receiving medical care through her state (North Carolina) meant that she had to serve as a teaching example at the clinic she went to for treatment. Therefore, she's had to relay her illness narrative over and over again.

pleasant doctor-patient encounters. Even with pain, fatigue, and other neurological symptoms, she was counseled by one neurologist to simply 'try harder.' "Neurologists are the biggest dicks of the medical world. I think they find themselves fancy."

After establishing her medical history, more or less, the chat turned to the topic of the queer closet as an analogy to discuss life with non-apparent disabilities:

NK: It's a very similar process, the conversations you have with families and employers, and hell, even medical professionals, because it's fairly common for queer folks in the closet to end up seeing a therapist at one point or another, because that lifestyle will drive you crazy.

Me: What has been more problematic for you personally? Do you get more support or understanding about one identity over the other?

NK: Definitely the physical aspects. They require a bit more from other people, and a bit more effort to hide. Not that hiding your sexuality is easy or enjoyable, but it involves some tricky pronoun work, explanations, etc., and not as much direct need for accommodation from the people you're trying to hide it from. I don't know that I got more support/understanding, but I was certainly given less grief about coming out as queer. That was kind of a flash in the pan, everyone is very upset about it, and then, if it's not right in front of their eyes, they tend to ignore it or justify it away, "a phase."

Me: Do you find that being ill is ever like that? Do people need 'reminding' because you don't 'look' any different?

NK: Oh yes. There's this ugly catch-22, this impossible balance to find. On the one hand, you can be very open with the fact that you're having problems. I'm tired. My joints hurt. I can't do that because I'm having trouble with x,y,z. And yes, then people are aware of it. But because it's chronic illness, not acute, they get reeeaaallly tired of hearing it. So then you've got the other hand, the one where you don't say anything. You try to continue on the best you can, but of course, there are still limitations. And so when you hit a serious roadblock and have to say "I can't do this," they tend to be a bit surprised and confused. "Where is this coming from?" And then there's a lot of eye rolling.

The experience of a double-bind is the defining feature of the 'third space' between the healthy and visibly impaired. Staying in the closet has consequences just as outing does. Even though she was adamant that the two identities caused similar social problems, it had never occurred to her to think of them this way until I pointed it out. I was very curious as to why that might be, so after much awkward prefacing on my part, I finally asked NK why she had never considered the similarities of the queer and disabled closets. She replied that the medicalization paradigm is so powerful, so engrained, that she simply never thought of it that way. And, she observed, "You don't have to lobby for people to *do* anything for you when you're queer as you do for accommodations."

It seemed to me, though I could be flattering myself, that the comparison was ultimately an empowering one for NK. Her replies seemed to come in a shade quicker than during other segments of our live chat conversation. As we continued to discuss the mechanics of the closet, I think the both of us realized that the comparison allowed us to verbalize the stigmas we'd felt in a way that society might actually understand. This was

my initial hope when I first considered the analogy, but since NK lives both the identities of queer and disabled, it was an enormous relief for me to know that she too found it helpful, instead of offensive or gratuitous.

CONCLUSION

> To say that someone is disabled in some way is not simply to say that he or she cannot do something, or some set of things: it is rather that he or she cannot do things that the speaker supposes individuals of that kind are supposed to be able to do. [39]

This thesis has sought to shed light on some of the obstacles that people with non-apparent disabilities must constantly navigate. Choosing when and how to out oneself as disabled is a constant concern with ramifications for family, work, and broader social life. Living with an ever-changing chronic illness is like standing on shifting sands; day to day life consists of struggling to function with fatigue, pain and other challenges while also attempting to perform one's various social roles. It is often an isolating experience, and made more so by the lessened legitimacy of embodied claims to suffering. In attempting to explain an insufficiently clear diagnosis to new doctors, friends, and others, many people find that the narratives of experts are in a much more authoritative position than their own to make claims about their bodies. Whether the experiences of suffering are alternatively defined by appeal to psychosocial factors or to broader sociopolitical and economic inequalities, the voice of the patient is frequently lost.

Utilizing the works of Goffman and Sedgwick has hopefully underscored the fact that the dynamics of stigma management and of the closet intertwine in unique ways. The

[39] Davis, "Invisible Disabilities," 157.

story of this closet is also a story of the double-bind: in trying to succeed, each move you make also causes you to fail. At the crux of the problem is the choice between the lesser of two stigmas; once a person's level of functionality degrades to the threshold of disability, the stigma of outing oneself as disabled may be less impactful than the stigmas associated with failing to adhere to social norms for no apparent reason. We are presumed healthy unless proven otherwise (Swain & Cameron 1999), and the expectations for the able-bodied are both formidable and increasing as more and more productivity is expected of us (Martin 1994; 2009).

In failing to perform to these expectations the moral judgments imposed upon one's character can be harsher than the stigma that comes with the 'disabled' label. Even though outing comes at a high cost for the 'invisibly' disabled and is often a process that must be endlessly repeated, the stakes for not maintaining this stigmatic label can be quite high. In this way, stigma itself can become a goal to be achieved rather than a status to escape. Further, the label itself can open up paths to desperately needed accommodations and social safety nets. Even so, people who suffer 'invisibly' still struggle with guilt and shame for claiming this status, because the dominant cultural paradigm of the disabled is still so predicated upon the model of the visibly impaired.

One of the most interesting insights gleaned from my survey results was that even though 100% of the 29 respondents would describe themselves as chronically ill, and a majority evaluated the level of their illnesses as disabling, only 10 people were totally confident that they were in fact 'really ill' and not just somehow lazy, or not trying hard enough. In addition, though everyone conceded that their illnesses seriously affected their ability to do major life activities like going to the grocery store, most would still feel

guilty about using a disabled parking tag, even if it would significantly help them to perform these life activities. The paradigm of the visibly, predictably, even 'healthy' disabled is a very, very powerful one.

But whether advocacy or 'visibility' increases, for the chronically ill there will always be day-to-day suffering until biomedicine can come up with better answers for what's going on with contested illnesses. There is a brisk business in holistic and alternative treatments for symptoms, and some people have found substantial relief this way. Many lay theories abound to explain the etiologies of chronic illnesses, and as such there are a multitude of strategies for affecting cures. Biomedical legitimacy for contested illnesses, therefore, can be seen as ultimately a means to an end. It is less a way for the ill to 'make sense' of their illness, nor is it necessarily a project to reify a philosophical concept of the mind/body split. Instead, it is chiefly a pathway to better treatments, and possibly some relief.

It is, then, essential that care providers and others also understand that the common initial resistance of patients to consider psychiatric or psychological pathways to treatment is not a refusal on their part to acknowledge that stress or depression can affect their bodies, but instead is a reaction against a long history of physicians displacing blame onto patients for their suffering. Without this understanding, people may be reluctant to seek treatment from their doctors for the depression or anxiety that necessarily attends being disabled and having to learn to live life in a drastically different way. The goal of the practitioner and the patient should thus be united towards the relief of suffering.

To make one last point: People who are not forced into the third space of non-apparent disability might be justified in wondering why it's so important for us to receive a social pass for failing to adhere to unspoken social norms, when the norms themselves are unfair and should really be questioned in the first place. Because it hurts other people besides ourselves. Yes, discrimination should be a thing of the past, but it's not. And if people don't realize what they are doing is discriminatory, they are probably only paying attention to the fact that you've disrespected them, betrayed their trust somehow, or that you don't want to spend time with them. Not only, then, have you hurt other people, but you are in the position of being unable to promise it will never happen again.

And despite the guilt, and then the shame, you can't help but also feel helpless and angry against perceptions of you character that you cannot change. “When we think of those who present a false front or 'only' a front, of those who dissemble, deceive, and defraud, we think of a discrepancy between fostered appearance and reality” (Goffman 1959:59). In my particular case, no one sees the mandatory 12 hours of sleep (that's half my life), the slow tortured climb out of bed, the 5 times I change clothes because I haven't been able to do laundry recently and I can’t make a decision on what to wear, the speeding ticket that I almost get trying to make it on time, the three square meals that I haven’t eaten today, or the daily handful of expensive pills that I have to take. But instead of my own story, I will let NK have the last word. When I asked her if she had anything to share that might help others to understand her situation, she shared the following:

> I think they need to understand that people live differently. Not everyone has the same abilities opportunities, and options as they do. And that trying to compensate for that (gay marriage; ensuring accessibility and accommodation,

government aid in the form of SSDI/Medicare/SNAP) is not “special treatment.” This is something that has been fought across decades, centuries, political factions, and cultures. It’s not new. And it still sucks.

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Appendix: Survey Questions

Survey title: Living with Non-Apparent Disabilities

[These substantive questions appeared after the initial "Basic Demographics" section]

Would you describe yourself as living with a chronic illness?

- Yes
- No
- Unsure, but probably
- Unsure, but probably not

Please choose the option that most broadly describes your illness:

- Mood disorders & other cognitive disorders (Bipolar, ADD/ADHD, etc)
- Chronic pain or other "diagnoses of exclusion" (Fibromyalgia, Chronic Fatigue Syndrome, etc)
- Auto immune disorders (Lupus, Celiac, Lyme disease, etc.)
- Other (Please describe)

Do you have access to health insurance?

- Yes
- No
- I did, but not anymore
- Yes, but only recently

Have you ever been diagnosed with a chronic illness?

- Yes
- Yes, but I don't agree with the diagnosis
- No
- No, but I think I should have

If you would like to elaborate on your answer to the previous question, you may do so here:

[text box]

[This next section asked respondents to rate each statement on a five-point scale from "**Very true**" to "**Not true at all**"]

My health negatively affects my ability to perform at work or in school.

My health makes it difficult to make plans for the future.

People are surprised to hear that I am chronically ill.

I often hear, "But you don't look sick!" or similar phrases.

I often feel pressure to prove to other that I am "really sick."

Even if I were issues a disabled parking tag, which could significantly improve my ability to get around or run errands, etc., I would still feel guilty using it.

I often wonder if I could try harder, or I worry that my problem is actually laziness.

My close friends and family are generally supportive and understanding about my health challenges.

My colleagues and/or coworkers are generally supportive and understanding about my health challenges.

My boss (professor, teacher, etc.) is generally supportive and understanding about my health challenges.

My doctor or health care provider is generally supportive and understanding about my health challenges.

I sometimes agonize over the need to "confess" or explain my health status to new friends or acquaintances in order to avoid potentially being judged later.

[This was the final question of the survey]

According to Sec. 12102 of the Americans with Disabilties Act (2008 [1990]), in order to qualify under U.S. law as "officially" disabled (for purposes of protections under the law, including possible benefits) you must have:

"a physical or mental impairment that substantially limits one or more major life activities; a record of such an impairment; or being regarded as having such an impairment."

Furthermore, it states that:

"An impairment that substantially limits on major life activity need not limit other major life activities in order to be considered a disability."

and also:

"An impairment that is episodic or in remission is a disability if it would substantially limit a major life activity when active."

Based solely on this definition, would you consider yourself "officially" disabled?

- Yes.
- No.
- Maybe.

[end of survey]